

SPINA BIFIDA

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Definition

Spina Bifida means cleft spine, which is an incomplete closure of the spinal column. There are three types of spina bifida:

1. **SPINA BIFIDA OCCULTA:** There is a opening in one or more of the vertebrae (bones) of the spinal column without apparent damage to the spinal cord.
2. **MENINGOCELE:** The meninges, or protective covering around the spinal cord, has pushed out through the opening in the vertebrae in a sac called the “meningocele,” but the spinal cord remains intact. This form can be repaired with little or no damage to the nerve pathways.
3. **MYELOMENINGOCELE:** This is the most severe form of spina bifida, in which a portion of the spinal cord itself protrudes through the back. In some cases, sacs are covered with skin; in others, tissue and nerves are exposed. People use the terms “spina bifida” and “Myelomeningocele” interchangeably.

Diagnosis

Spina bifida can be diagnosed during pregnancy or after the baby is born. Spina bifida occulta might not be diagnosed until late childhood or adulthood, or might never be diagnosed.

History

Approximately 40% of all Americans may have spina bifida occulta¹, but very few ever know that they have it. Meningocele and myelomeningocele are known collectively as “spina bifida manifesta,” and occur in approximately 1/1000 births. About 96% of the infants with spina bifida manifesta have the myelomeningocele form².

The effects of myelomeningocele may include muscle weakness, paralysis or loss of sensation below the area of the spine where the incomplete closure (cleft) occurs, and loss of bowel and bladder control. About 70-90% of children born with myelomeningocele have hydrocephalus, or accumulation of fluid in the brain. Hydrocephalus is controlled by a surgical procedure called “shunting,” which relieve the pressure of fluid buildup in the brain, thereby lessening the risk of brain damage, seizures, or blindness. This surgery can be performed as early as the first 48 hours of life.

Education Impact

Mobility and Physical Activity

The spectrum of mobility depends on the location of the spina bifida and could present as being:

- Fully ambulatory
- Assisted with braces, walkers, crutches or
- Wheelchair

No two children with spina bifida are exactly alike. Health issues will be different for each child. Some children have issues that are more severe than other children. School nurses need to collect a complete health history for a child with spina bifida. This will guide the care plan and interventions necessary for the student to be successful in school. See below for general suggestions.

School programs should be flexible to accommodate the special needs of children with spina bifida. Some options that are available to schools include:

504 Plan and/or Individual Health Care Plan

Parents can request a 504 Plan hearing to determine eligibility for their child. School nurses should understand the local SAU policy for 504 determinations. By law, children may be eligible to have a 504 Plan which lists accommodations related to a child's disability. The 504 Plan accommodations may be needed to give the child an opportunity to perform at the same level as their peers. For example, a 504 Plan may include the child's assistive technology needs, such as a tape recorder or keyboard for taking notes and a wheelchair accessible environment.

Individualized Education Plan (IEP)(Special Education)

Children who participate in special education classes will have an IEP. An IEP is a legal document that lets the school know what kinds of accommodations or assistance will be needed by a child during the school day. An IEP is created by parents and school personnel, such as a psychologist, teachers, a school nurse, and a physical education teacher, as well as any other professionals that parents think might be helpful. A health care plan (IHP) can be part of the IEP process and documents. A copy of the IHP should be in the student's permanent school health record.

Role of the School Nurse

- Collect a complete health history
- Obtain a medical release to speak with providers to develop a health care plan (IHP)
- Provide private space and supply storage for bowel and bladder care
- Provide shunt care as medically directed

- Assist student based on age and ability
- Educate staff about spina bifida and latex allergy
- Inform parents of 504 determination process
- Participate in the 504 process as a member of the 504 team
- Educate school staff about the potential physical and academic deficits. Students may demonstrate math and reading deficits
- May qualify for other health related services (i.e. OT, PT)
- Inspect adaptive equipment for function and safety (crutches, wheelchairs, shoes)
- Facilities modifications may be required to accommodate students with adaptive equipment
- Check students with spina bifida for skin integrity (breakdown)

Resources

US CDC Spina Bifida site - <http://www.cdc.gov/ncbddd/spinabifida/>


Spina Bifida Association (SBA) www.spinabifidaassociation.org

SBA of Greater New England (Formerly SBA of Massachusetts) covers Maine
219 East Main St Suite 100B Milford, MA 01757 Phone: 508-482-5300 Toll Free: 888-479-1900 Fax: 508-482-5301 Email: edugan@sbaMass.org Web: www.sbaMass.org

Kids Health http://kidshealth.org/parent/system/ill/spina_bifida.html


- A [Spina Bifida Association \(SBA\) Chapter](#) is a great place to connect with other families. The SBA website can provide information on how to find a local chapter.
- The [Spina Bifida Association Listservs](#) bring people together online to discuss topics such as parenting a child with spina bifida and growing up with spina bifida.
- [Parent to Parent Programs](#) provide information and emotional support to families of children who have special needs.
- [National Resource Center](#): Get information and find clinics or health care providers who are experts in spina bifida.
- [Preparations Website](#): Resource about becoming an Adult Living Successfully with Spina Bifida


For more information, please visit the Spina Bifida Association website:


Educational Issues Among Children with Spina Bifida 

Learning Among Children with Spina Bifida 

Learning and Education Information for Parents, including IEP and 504 Plans 

Example of a 504 Plan 

Reading Comprehension Difficulties and Spina Bifida 

Math Difficulties and Spina Bifida 

Latex Allergy -

http://www.spinabifidaassociation.org/site/c.liKWL7PLLRf/b.2700271/k.1779/Latex_Natural_Rubber_Allergy_in_Spina_Bifida.htm

References

1. <http://nichcy.org/disability/specific/spinabifida>
2. <http://nichcy.org/disability/specific/spinabifida>